

**GOVERNOR'S ADVISORY COUNCIL FOR EXCEPTIONAL CITIZENS (GACEC)
GENERAL MEMBERSHIP MEETING**

7:00P.M., May 17, 2016

**George V. Massey Station, Second Floor Conference Room
516 West Loockerman Street, Dover, DE**

MINUTES

MEMBERS PRESENT: Chairperson Robert Overmiller, Dafne Carnright, Carma Carpenter, Nancy Cordrey, Cathy Cowin, Bill Doolittle, Karen Eller, Ann Fisher, Lisa Gonzon, Brian Hartman, Emmanuel Jenkins, Sonya Lawrence, Karen McGloughlin, Chris McIntyre, Carrie Melchisky, Mary Ann Mieczkowski, Beth Mineo, Jennifer Pulcinella, Shawn Rohe, Brenn  Shepperson and Kirsten Wolfington.

OTHERS PRESENT: Guests: Tracy Neugebauer (DOE), Sandi Miller (DVR), Aquiles Iglesias (UD SLP Program), and Jacquie Truluck (UD SLP Program).

Staff present: Kathie Cherry, Office Manager; Sybil White, Administrative Coordinator.

MEMBERS ABSENT: Al Cavalier, Jane Donovan, Bernie Greenfield, Terri Hancharick, Thomas Keeton, Dana Levy, Keith Morton, Bill O'Neill, Ron Russo, Howard Shiber, Lavina Smith.

Chairperson Robert Overmiller called the meeting to order at 7:05p.m. Robert announced that Wendy Strauss would not be joining the meeting this evening due to surgery. Robert asked for any additions or deletions to the agenda. Being there were no revisions, **a motion** was made to accept the agenda as written and the **motion was approved.**

A **motion** was made to approve the April minutes, with one correction. Beth Mineo was present at the April meeting but was not listed as such in the minutes. The **motion was approved.**

A **motion** was made to accept the April financial report. The **motion was approved.**

Public Comments

There were no public comments

Robert announced guest speakers Dr. Aquiles Iglesias and Jacquie Truluck from the University of Delaware's Speech Language Pathology Program. Dr. Iglesias and Ms. Truluck gave an overview of the program that will welcome its first class of students in the fall of 2016. The class currently has 27 students enrolled. Dr. Iglesias pointed out that nine of those students are local. The program is working closely with local partners like Christiana Hospital and local school districts for externship sites. At the moment only in-state externships sites are acceptable, though this may change. The program is already seeing a small number of patients at the clinic. The hope is to provide students with a wide range of clinical experiences, including pediatrics and geriatrics. Council members were invited to visit the center or contact either Ms. Truluck or Dr. Iglesias with any questions.

DOE REPORT

Mary Anne delivered the DOE report which is outlined below:

Enhancing Advocacy Skills of Educational Surrogate Parents

An Education Surrogate Parent (ESP) is appointed to serve as the parent of a foster child for the purpose of the IEP process. Each ESP is required to complete specific training requirements to ensure that they are fully prepared to advocate for their student. This school year, a new requirement was added to increase understanding of the Common Core State Standards.

Trainings were held on April 5th and April 12th:

- 90.91% of attendees reported that they had a better or somewhat better understanding of the Common Core State Standards as a result of the training.
- 45.45% of attendees reported that they need to learn more about the Common Core State Standards.

National Recognition for Exceptional Children Resources (ECR)

For the past two years, DOE staff, LEA staff, parents, state agencies and various stakeholder groups have engaged in the work of the State's IDEA State Systemic Improvement Plan. As word began to spread to other states about the great work being done in Delaware, ECR began being invited to present at Office of Special Education Programs (OSEP) sponsored conferences and cross-state collaboratives.

New and Improved IEPPLUS

- Exceptional Children Resources has been working closely with SunGard to improve the current IEPPLUS 4.3 system in areas such as user engagement and functionality. LEAs have reported improvements in speed, accessibility and immediate integration between PLUS360.
- In addition, four LEAs, "early adopters", are piloting IEPPLUS 5 which is an entire rewrite of the IEPPLUS program. This new version includes many features that were requested by users such as auto save, multiple users being able to work on the same IEP at the same time, mobile access on various devices, additional browser capabilities, inclusion of charts and graphs and formatting of text. Representatives from the early adopters have been working with Exceptional Children Resources and SunGard since September to customize the system to Delaware's needs in preparation for the April 4th launch.
- Parents and students have also been part of the process.
 - ~ Parent feedback groups were held in each early adopter LEA to obtain input on the IEP document and progress reporting format.
 - ~ Parents are being asked to complete a short survey at the conclusion of the IEP meeting to identify any issues with the software based on their experience.
 - ~ Secondary students are working with Dale Matusevich to redesign the student invitation to their IEP meeting.

The pilot will be evaluated in June after which the Department will work with SunGard and LEA Special Education Directors to plan for the next school year.

Project SEARCH – New Castle County – Superstars in Education Award
Red Clay Consolidated School District

The Delaware Department of Education (DOE), Delaware Department of Labor Division of Vocational Rehabilitation (DVR), Red Clay Consolidated School District and Christiana Care have been working together over the past five years to advance the Christiana Care Way by employing a diverse workforce that is representative of our community, while knowing it was essential to identify opportunities to remove employment barriers for individuals with disabilities. An opportunity to collaborate with the state's education system and community providers to provide young adults with cognitive disabilities the opportunity to develop competitive job skills necessary for employment through Project Search seemed like a natural fit and gave Christiana Care greater access to an untapped labor pool with limitless potential. *For the 2015-2016 school year, this opportunity was expanded to all of New Castle County School Districts.*

Christiana Care Health System (CCHS) was the first employer in the state of Delaware to partner with a nationally recognized program dedicated to workforce development focused on individuals with cognitive disabilities that often lead to significant barriers to employment. Our partners in Project SEARCH are Community Integrated Services (CIS), Autism Delaware, Red Clay Consolidated School District, the State of Delaware's Department of Education and Department of Labor, Division of Vocational Rehabilitation.

Overall, during the first four years, the CCHS Project SEARCH program hosted a total of 29 interns, of which, 23 individuals have successfully secured employment, with 12 of them hired by Christiana Care Health System.

For the current year (Year 5), 12 interns began the year with three interns already accepting positions with Christiana Care. Six additional interns are in the process of applying for positions. One intern will enroll in a 14 week culinary arts program. One intern found employment outside of Project SEARCH; and the remaining intern has enrolled in an outside program.

As we approach the 2016-2017 school year, Project SEARCH – New Castle County will again be enrolling the maximum (12) number of interns.

On May 9, 2016, Project SEARCH received a 2016 Superstars in Education Award.

CHAIR/DIRECTORS REPORT

Robert explained that Wendy would not be with us tonight due to medical leave. Robert mentioned that a member email list is being passed around for members to verify their email addresses. Robert announced that committee report submissions for the annual report are due no later than July 8, 2016.

COMMITTEE REPORTS

ADULT TRANSITION SERVICES

Guest speakers for the evening cancelled so the group came up with some questions about the ABLE Act. Chair Cathy Cowin will email the questions to Rick Kosmalski for answers. The group discussed a possible bill for increased expectations for graduation for middle and high school. The group is hoping to have a life skills program requirement in the legislation.

CHILDREN AND YOUTH

Karen Eller reported that Tracy Neugebauer spoke to the committee on supporting students with behavioral needs. She discussed some of the featured initiatives in the state such as the State Personnel Development Grant (SPDG). The group discussed some of the positive experiences that are being reported by the program. Karen stated that the group would like to start their monthly committee meetings at 5:30 instead of the traditional 6:00 start time.

INFANT AND EARLY CHILDHOOD

Jennifer reported that the group discussed the recent meetings with Matt Denn and Susan Perry-Manning regarding medical issues being lost in the transition from Part C to the school districts. Jennifer indicated that the group would like to do a Freedom of Information Act (FOIA) request to get a copy of the Memorandum of Understanding (MOU) between DOE and New Castle County Schools. The group would also like to get a list of districts that provide itinerant services for pre-school. Brian Hartman suggested and Mary Anne agreed, that rather than submit a FOIA request, Mary Ann can provide a copy of the MOU.

POLICY AND LAW

The committee agreed to take action consistent with the recommendations in the May 9, 2016 Policy and Law memo on items 6-17, with the following modifications:

- Item 13 - add observation that bill could have unintended consequences of deterring expectant mothers with addictions from seeking treatment, or having delivery at a hospital.
- Item 16 - Council would endorse the concept of legislation.

Commentary from the legal memorandum was as follows:

6. DOE Final Meeting Minutes & Prior Notice Reg. [19 DE Reg. 1018 (5/1/16)]

GACEC commented on the proposed version of this regulation in February.

Meeting Minutes

First, the Council noted that limiting a parent's right to take minutes to meetings concerning a Free Appropriate Public Education (FAPE) was "under inclusive" given a broader authorization under State law and another DOE regulation. The DOE effected no change. We continue to believe the regulation is not consistent with the statute and other regulations.

Second, the Council recommended that the DOE require that parents be offered a "free" copy of minutes and that the parents have a choice of a "paper" or digital copy. The DOE inserted the word "free" but limited the copy to a digital version.

Prior Notice

First, the Council noted that state law requires a notice to include "a full, written explanation of all the procedural safeguards available to parents under state or federal law or regulations". The DOE proposed to delete the regulation which mirrored this statute and simply say a "summary" must be "available". The DOE declined to retain the current compliant regulation. This is very unfortunate since parents will not be given an explanation of their rights prior to a meeting to help them prepare. Under the new DOE regulation, the rights could be shared at the end of the meeting, a highly disfavored approach.

Second, the Council observed that only imposing notice requirements on IEP teams was inconsistent with statutory law which required "agencies" to issue conforming notices. There may be district and charter school notices issued by entities other than an IEP team. The DOE declined to "fix" the problem.

Third, the Council recommended inserting three statutory references at the end of §3.0. The DOE agreed and inserted the references.

Council may wish to consider requesting a copy of the comments submitted by the Attorney General's Office (at 1018) and, after review, consider whether to request an Attorney General's opinion on the compatibility of the regulations with statutory law.

7. DOE Revised Proposed IEP Regulation [19 DE Reg. 969 (5/1/16)]

The Department of Education issued an initial proposed regulation amending its IEP standards in February, 2016. GACEC commented on that initiative.

The committee discussed the following observations.

First, the DOE incorporates edits verbatim based on the “First” and “Third” recommendations in the February letter.

Second, in its February letter, the Council identified a “disconnect” between §22.2.3 and State statute, 14 Del.C. §3134(1). The DOE permits “offering” (but not automatically providing) a copy of procedural safeguards at the conclusion of an IEP meeting. The statute contemplates provision of the procedural safeguards with the notice (§3134(1)). The DOE views a “notice of meeting” as not covered by §3134(1). At 969. This makes little sense. Even if arguably permitted under federal law, State law can exceed minimum federal standards. Consider the following:

A. Section 3134(8) contemplates a norm of schools providing a copy of the proposed IEP with the notice. This ostensibly represents a proposal to change a student’s FAPE and Section 3133 therefore requires issuance of a §3134-compliant notice, i.e., one which includes “a full explanation of all of the procedural safeguards available to the parents under state and federal law and regulations.”

B. If the compliant notice is not provided prior to the meeting, the parent will not be aware of sources of legal and other assistance (e.g. DLP; PIC) [§3134(6)]; recent test and evaluation results [§3134(3)]; and other factors underlying the proposed changes to the IEP [§3134(4)].

C. Providing information about rights at the conclusion of an IEP meeting, rather than prior to the meeting, undermines effective parental participation. It is inherently a dysfunctional approach to promoting informed parental participation in the meeting.

The committee recommends sharing these observations with the DOE, State Board of Education (SBE) and the Attorney General.

8. DOE Proposed School Nurse Regulation [19 DE Reg. 979 (5/1/16)]

The Department of Education proposes to adopt some discrete revisions to its school nurse standards. The rationale is as follows: “This regulation requires some formatting changes to conform to other Standard Certificates and the updating of certification requirements.” At 979.

The committee had only one observation. The DOE may wish to reconsider §6.2. That section requires public schools to be responsible “for verifying that the School Nurse continues to meet the requirements” in certain subsections. The reference to §4.1.1 seems inapt since a nurse will not “lose” a degree. On the other hand, it may be logical to include a reference to §4.1.4 since the 90 hours of mandatory training would occur subsequent to hiring. Therefore, the DOE could consider substituting “subsections 4.1.2 through 4.1.4” for “subsections 4.1.1 through 4.1.3” in §6.2.

The Council may wish to share these observations with the DOE and SBE.

9. DOE Proposed “Emotional Disability” Regulation [19 DE Reg. 967 (5/1/16)]

The Department of Education proposes to adopt a discrete change to the “definitions” section of its IDEA regulations. In a nutshell, it is substituting “emotional disability” for “emotional disturbance”. At 968-969. No rationale is provided.

The current reference to “emotional disturbance” is based on the federal IDEA regulation, 34 C.F.R. §300.8. In adopting regulations in 2006, the U.S. Department of Education provided some background on the term which it noted has remained unchanged since 1977. See 71 Fed Reg 46550 (August 14, 2006). The term “disability” is arguably less pejorative than “disturbance” since “disturbance” has a more “negative” connotation than “disability”. Colloquially, characterizing someone as “disturbed” is generally viewed as derisive or ridiculing.

At least one other state, Virginia, has ostensibly adopted “emotional disability” in its IDEA regulations. The Delaware DOE indicates that it views the terms “emotional disturbance” and “emotional disability” as “equivalent”. At 969.

The Council may wish to either endorse the substitution of terms or comment that there is no objection to the substitution.

10. DMMA Prop. Spousal Impoverishment Undue Hardship Reg. [19 DE Reg. 987 (5/1/16)]

The expense of nursing home care - which ranges from \$5,000 to \$8,000 a month or more - can rapidly deplete the lifetime savings of elderly couples. In 1988, Congress enacted provisions to prevent what has come to be called “spousal impoverishment,” leaving the spouse who is still living at home in the community with little or no income or resources. These provisions help ensure this situation will not occur and that community spouses are able to live out their lives with independence and dignity.

There is a federal minimum resource standard which is updated annually. In 2016, it is \$23,844. States can exceed the federal minimum. Delaware adopted a standard of \$25,000 in 1993.

Federal law, 42 U.S.C. 1396r-5(c)(3) directs states to disregard otherwise countable spousal resources if “the State determines that denial of eligibility would work an undue hardship.” DMMA’s current regulations implement this law:

An institutionalized spouse who (or whose spouse) has excess resources shall not be found ineligible per Section 1924(c)(3) C of the Social Security Act where the state determines that denial of eligibility on the basis of having excess resources would work an undue hardship.

16 DE Admin Code 20950. See also 19 DE Reg. at 989.

DMMA proposes to adopt the following definition of “undue hardship”:

20900.1. Undue Hardship

Spousal Impoverishment rules may be waived if the application of the rules would cause an undue hardship. Undue hardship exists when application of the spousal impoverishment provisions would deprive the individual of medical care such that his/her life would be endangered. Undue hardship also exists when application of the spousal impoverishment provisions would deprive the individual of food, clothing, shelter or other necessities of life.

The committee discussed two observations.

First, DMMA should consider an increase in the \$25,000 resource cap adopted in 1993. Consistent with the data discussed, \$25,000 in 1993 is equivalent to \$41,199 in 2016. If raised, there would be less need to consider a waiver.

Second, the proposed standard is unduly limiting. Medical expenses can qualify for consideration in the “undue hardship” determination only if the individual would die without the medical care. CMS is more expansive, authorizing an “undue hardship” waiver if the person’s health would be endangered. Thus, if the loss of medical care would result in excessive pain; loss of a limb; partial paralysis; exacerbation of a diagnosed mental health condition (e.g. depression; schizophrenia); or other deterioration in health, the DMMA workers should be able to consider such effects. Moreover, it would be preferable to modify the third sentence as follows: “Without limitation, undue hardship also exists when application....life.” There should be some recognition that genuine hardship may be presented by factors beyond a short list. For example, a blind individual with an aging seeing-eye dog may need funds for dog food and expensive veterinary care.

The Council may wish to share these observations with DMMA with a courtesy copy to AARP.

11. DMMA Proposed ABLE Account Regulation [19 DE Reg. 982 (5/1/16)]

The Division of Medicaid & Medical Assistance proposes to adopt regulations implementing the Achieving a Better Life Experience Act of 2014 (“ABLE” Act). The Act authorizes the establishment of a special account for the benefit of a qualifying individual with a disability. Funds in such an account which will not be a countable resource and distributions from such a fund for a qualified disability expense (“QDE”) are not countable income for public benefits programs. Implementing State legislation was adopted in 2015 and is codified at 16 Del.C. §§9601A- 9608A. New state legislation (H.B. No. 358) was introduced on May 4, 2016.

The committee discussed the following observations on the proposed regulation.

First, in §20330.2.1.1, the definition of “person with signature authority” merits reconsideration. The first sentence reads as follows:

“Person with signature authority” means a person who can establish and control an ABLE account for a designated beneficiary who is a minor child or is otherwise incapable of managing an account.

The federal regulations do not require an adult to “be incapable of managing an account” to designate a “person with signature authority. See, e.g., the proposed regulation published at 80 Fed Reg. 35611 (June 22, 2015):

If the designated beneficiary is not able to exercise signature authority over his or her ABLE account or chooses to establish an ABLE account but not exercise signature authority. references to the designated beneficiary with respect to his or her actions include actions by the designated beneficiary’s agent under a power of attorney or, if none, a parent or legal guardian of the designated beneficiary.

[emphasis supplied] A “competent” adult can simply choose to not exercise signature authority.

Second, in §20330.2.1.1, the definition of “ABLE program” refers to a program established or maintained “by a State (or agency or instrumentality thereof)....”. This is consistent with the proposed federal regulation. See 80 Fed Reg. at 35612(June 22, 2015). However, we understand that many states are contemplating implementation through a consortium of states. Therefore, DMMA could consider expanding the reference as follows: “by a State or consortium of states (or agency or instrumentality thereof)...”.

Third, for similar reasons, DMMA could consider amending the definition of “eligible individual” as follows: “ a resident of this State, a contracting state, or a state participating in a consortium arrangement who is:...”

Fourth, for similar reasons, DMMA could consider amending §20330.2.1.2.2 as follows: “The State or consortium ABLE program that is administering the account.”

Fifth, in §20330.2.1.1, the definition of “eligible individual” requires the person to be a resident of Delaware or “a contracting state”. The proposed federal regulation would allow some persons (e.g. military) to keep an account even if the person is no longer a resident of the state. See 80 Fed. Reg. at 35608. Therefore, there is some “tension” between the “residency” requirement and the proposed federal regulation. Moreover, consistent with a January 11, 2016 article, Congress amended the law so an eligible person can open an account in any state, regardless of where the person resides.

Sixth, in §20330.2.1.3, second sentence, there is a plural pronoun (“their”) with a singular antecedent (“person”). This can be easily corrected by substituting “the person’s” for “their”.

Seventh, in §20330.2.1.5, correct the grammar by substituting “the beneficiary’s” for “their”.

Eighth, §§20330.2.1.6.1 and 20330.2.1.6.2 treat distributions for housing less favorably than other distributions. If a housing distribution is made on May 31 and paid to a landlord on June 1, the entire housing distribution would be considered a countable resource for the month of June. This is an unreasonable approach.

The committee recommends sharing these observations with DMMA and policymakers with a courtesy copy to the AARP.

12. House Bill No. 302 (Texting & Hand-held Cell Phone Use While Driving Penalties)

This legislation was introduced on April 6, 2016. As of May 9, it awaited action by the House Public Safety & Homeland Security Committee.

Under current law, a driver using an electronic communication device while a vehicle is in motion is subject to a \$50 civil penalty for a first offense and \$100-\$200 civil penalty for a subsequent offense. No points are assessed. See lines 4-8. House Bill No. 302 would enhance penalties as follows: \$100 civil penalty for first offense and \$200-\$300 civil penalty for subsequent offense. House Bill No. 302 would also authorize imposition of points for second or subsequent offenses.

Anyone traveling on Delaware roads routinely observes drivers flagrantly violating the law. The \$50 civil penalty is so modest that there is little deterrent effect. Moreover, driving while texting or using a hand-held device greatly increases the risk of accidents and injuries.

Given the above considerations, the Council may wish to consider issuance of a favorable analysis.

13. House Bill No 319 (Substance Exposed Infants)

This legislation was introduced on April 13, 2016. As of May 9, it had been released from the House Judiciary Committee and awaited action by the House. It is earmarked with an incomplete fiscal note.

Similar legislation (H.B. No. 268) was introduced in March, 2016 and stricken on April 14, 2016. House Bill No. 319 omits some provisions involving “medically fragile children” which were highly disfavored by the Council. However, in some other respects, House Bill No. 319 replicates some problematic provisions in the prior bill.

In a nutshell, approximately 3% of babies born in Delaware qualify for a diagnosis of neonatal abstinence syndrome (NAS) in which the infant undergoes opiate withdrawal. That percentage has been growing in recent years. Indeed, DFS predicts that 600 babies will be born with NAS in Delaware in 2016. DFS substantiates abuse in approximately 10% (44/448) of cases of suspected neglect or abuse reported to it among babies born with drugs or alcohol in their system. Medical

professionals prefer to place pregnant women with addictions on methadone resulting in only short-term effects on babies treated for withdrawal upon birth.

House Bill No. 319 (lines 79-90) would require health care providers to report to the Division of Services for Children, Youth and their Families (DSCY&F) infants affected by either: 1) illegal substance abuse by the infant's mother; 2) withdrawal symptoms resulting from prenatal drug exposure (with exceptions); or 3) fetal alcohol spectrum disorder. Although reports of abuse or neglect can generally be made anonymously, this is not permitted for reports of substance exposed infants (lines 108-110). A "plan of safe care" would be developed for cases accepted by DFS for investigation or family assessment (lines 44-60 and 136-137).

The committee discussed the following observations.

First, the legislation reinforces an autocratic model in which the State imposes requirements and offers only modest help to new mothers with substance abuse profiles. The bill (lines 44-60) contemplates unilateral development of the "plan of safe care" with zero input from the parent. This "top-down" plan is then shared with agencies but not the parent (lines 48-49 and 56-58). This Kafkaesque approach is not a collaborative model which "engages" the new mother in a joint venture to benefit her infant. The "plan of safe care" section should preferably be amended to ensure parental input and collaboration in development of the plan.

Second, the articles describe successful outcomes for parents receiving wrap-around services while highlighting the paucity of resources available to many parents:

Holly Rybinski, of Newport, said she had to go to jail in order to get the drug treatment she needed. That was almost two years ago. She had stayed clean for five years, but while she was pregnant with his child, her partner overdosed and died. Consumed with grief, Rybinski turned to heroin and cocaine during the last five months of her pregnancy. After she gave birth to her son James on April 8, 2014, at Christiana Care's Wilmington Hospital, she was ready to be clean. She said the Division of Family Services told her that they had to take custody of him since James tested positive for drugs, she wasn't in a treatment program and Rybinski had a record. They told her she had 90 days to find employment, treatment and stable housing and then they could discuss putting him back in her care. That request was easier said than done. ... "I tried five different times to get into treatment," Rybinski said. "It was one obstacle after the other." As the number of pregnant and addicted mothers grows, the need for treatment is even more critical. Community members, families and those now in recovery, like Rybinski, have long lamented Delaware's lack of residential treatment options. Many people have to wait days and even weeks to get a bed. ...Currently, there is one state-run treatment program for expectant or new mothers recovering from addiction in Delaware, but it is only for women who are incarcerated and it is in Newark. ...Brandywine Counseling ran a program for expecting moms wrestling with addiction, called Lighthouse, downstate in Ellendale, but it closed in September due to budget cuts and staffing shortages. ... (It) was extremely successful. Nearly

100 percent of women were able to give birth to babies free of drugs.
“More treatment key for addicted moms”, Delaware News Journal (March 4, 2016).

Given the incomplete fiscal note, it is difficult to assess whether the legislation will expand resources. Obviously, successful outcomes for both mothers and infants are highly dependent on the ready availability of a comprehensive, responsive system of supports.

Third, the “plan of care” section identifies a few types of support services (lines 51-56). It could be improved by adding “safe housing” as a support service. This section also contemplates the identification of family supports (line 50) without including which entity will assure provision of the supports. Merely identifying “available family supports” (lines 50-51) without clarification of the agency responsible for assuring provision of the supports will result in ambiguity and plan failure.

Fourth, the Judiciary Committee Report indicates that the bill was supported since “it provides essential support for families”. In contrast, the text of the bill includes some relatively anemic standards and expectations. For example, lines 123-124 recite that “(t)he system shall endeavor to coordinate community resources...”. There is no definition of “the system” and the reference to “endeavor” (a/ka “try”) establishes a weak expectation. The sentence could be improved by reciting that “(t)he Division shall coordinate community resources...” OR “(t)he Division shall ensure coordination of community resources...”. Likewise, the plan of safe care contemplates simply a “referral” to substance disorder treatment programs and home visiting programs (lines 52 and 54). It would be preferable to include a more affirmative Division role in securing access to such supports than simply issuing a referral.

Fifth, lines 66-69 suggest that mothers prescribed Methadone (who would still have given birth to infants undergoing withdrawal) are exempt from the operative provisions in the bill. Their babies would not qualify under the definition of “substance exposed infant” (lines 61-63) since they are excluded from the definition of “withdrawal symptoms resulting from prenatal drug exposure” (lines 62 and 66-69). This approach is reinforced by lines 83-89. Reasonable persons might differ on the prudence of this approach since there would be no report to DSCY&F. Moreover, such infants would be categorically ineligible for a “plan of safe care” since such a plan is only available to a “substance exposed infant” (line 45).

The Council may wish to share conforming commentary with policymakers.

14. House Bill No. 311 (Mental Health Transition Plan)

This legislation was introduced on April 12, 2016. As of May 9, it awaited action by the House Judiciary Committee.

The key authorization in the bill (lines 4-7) is as follows:

When a child 17 years of age or older is in the custody of DSCY&F, the Court may order the Department of Health and Social Services to determine whether the child qualifies for adult mental health or behavioral services and, if so, to coordinate with DSCYF to develop and implement a transition plan for mental or behavioral health services for the child.

The plan would include any adult mental health or behavioral health diagnosis, list the prospective adult services for which the child might qualify, and include other information or relief the Court determines relevant to the child's transition to adulthood. See lines 7-10.

The committee discussed the following observations.

First, the transition of minors served by the DSCY&F Division of Prevention and Behavioral Health Services (DPBHS) to the DHSS Division of Substance Abuse & Mental Health Services (DSAMH) has been a matter of concern for decades. The most significant "tension" between the juvenile and adult systems results from more restrictive eligibility standards in the adult system. For example, the DPBHS serves minors with a wide array of mental health diagnoses while DSAMH has traditionally focused eligibility on persons with severe and persistent mental illness (SPMI). Compare DPBHS eligibility standards with DSAMH long term care (LTC) eligibility standards. DSAMH generally views SPMI to cover certain diagnoses, i.e., schizophrenia, depression, bipolar disorder, and personality disorder. Id. Other DHSS mental health programs (e.g. PROMISE) also have rather prescriptive eligibility standards based on specific diagnoses.

Second, the current DPBHS Strategic Plan is published at <http://kids.delaware.gov/pdfs/pbh-StrategicPlanCY13-16-update-2016.01.05.pdf> . The excerpt identifies transition from the juvenile to the adult mental health services system as a priority and describes the following initiatives addressing this priority:

- PBH is participating on a youth transition workgroup led by Judge Nicholas in Kent County.
- Project CORE was awarded to PBHS. This is a SAMSHA grant, in concert with DSAMH, to prevent psychosis in youth and young adults and to assist with the transition from youth BH services to the adult BH system.

If not already done, the sponsors of the legislation may wish to assess the status of the "youth transition workgroup" and SAMHSA-funded project addressing transition.

Third, House Bill No. 311 has the following positive features:

A. It would cover transition of youth not only in DPBHS custody, but also in DFS and YRS custody.

B. It provides a mechanism to ensure the collaboration of DSCY&F and DHSS in developing a transition plan so transitioning youth do not “fall through the cracks”.

C. DHSS has been expanding its mental and behavioral health services support system in recent years. The system has become increasingly complicated and involves a wide array of programs and providers. For example, DMMA-regulated Medicaid MCOs provide mental health and behavioral health services. The federal Court Monitor has been critical of the lack of coordination among the MCOs, DMMA and DSAMH while noting some recent improvement. DMMA administers the Community Alternative Disability Program Medicaid program with eligibility up to age 19. See 16 DE Admin Code 25000. The PROMISE program is still in its early stages of implementation. Simply referring a 17 year old (with mental health limitations) to programs will result in a “bewildered” youth who may simply “give up” on trying to navigate the system. Development of a judicially-prompted plan should ensure a smooth transition for such youth.

The Council may wish to share these observations with policymakers, including DHSS Administration, DSCY&F Administration and the Office of the Child Advocate.

15. House Bill No. 310 (Family Court Jurisdiction: Outpatient Treatment)

This legislation was introduced on April 12, 2016. As of May 9, it awaited action by the House Judiciary Committee. It is earmarked with an incomplete fiscal note.

The bill would expand the jurisdiction of the Family Court. A petition could be filed affecting a youth in DSCY&F custody upon turning 18 with a mental illness diagnosis (lines 8-11, 93-100). The petition could be filed when the respondent is between 17 ½ years of age through 20 ½ years of age (lines 10-11) and court jurisdiction could continue until the youth’s 26th birthday (lines 12 and 80-81). A wide array of entities could file the petition, i.e., DHSS, DSCY&F, the youth, youth’s attorney, or current or former guardian ad litem (lines 17-18). The Court would, at least on an annual basis, conduct a review of the youth’s circumstances (lines 50-65). The Court would be authorized to order the youth to participate in services or outpatient treatment (lines 66-69). If the youth fails to comply, the youth could be committed to a mental hospital (lines 78-79). The youth could also ostensibly be jailed under the Court’s criminal contempt authority. See line 79 and Title 10 Del.C. §925(3).

The committee discussed the following observations.

First, outpatient mental health commitment is an outdated and disfavored approach in the mental health system. The federal Court Monitor has been highly critical of Delaware’s historical “overuse” of outpatient commitment.

Second, the Family Court has previously been authorized to exercise extended jurisdiction when it would facilitate access to services, i.e., the Court can direct agencies to provide support services to dependent and neglected youth up to age 21 [10 Del.C. §929]. This feature is absent from this bill. Indeed, the bill explicitly eschews any support role of the DSCY&F once a youth reaches 18 (lines 90-

91). As a result, the bill is purely an autocratic vehicle to promote forced treatment of individuals who happen to have a mental health diagnosis.

Third, recognizing the fundamental liberty interests implicated in analogous civil commitment and guardianship proceedings, the judiciary and Legislature require a host of procedural safeguards. Such safeguards are absent from the bill. Consider the following:

A. There is no right to appointed counsel for the youth in initial proceedings (lines 30-31). It strains credulity to presume that a 17 - 20 year old with mental health limitations will be able to effectively self-represent in covered proceedings. Moreover, initial proceedings are not benign. They involve authorizing Court oversight of every conceivable aspect of the youth's life for an eight-year period (lines 56-65) and the prospect of involuntary orders if the Court disfavors the youth's choices. In later proceedings the Court may offer the youth an attorney rather than appointing counsel (lines 69-71). Query whether a youth with mental health limitations will be able to knowingly and intelligently waive counsel. Contrast 16 Del.C. §5007(3). Cf. Title 12 Del.C. §3901(c) and Chancery Court Rule 176 [Chancery Court automatically appoints counsel for persons subject to involuntary loss of autonomy via guardianship]

B. There is no right to an independent expert witness to contest either the diagnosis or need for involuntary treatment. Contrast 16 Del.C. §5007(3).

C. There is no explicit right to conduct discovery or invoke the right against self-incrimination. Contrast 16 Del.C. §5007(4).

D. The description of initial proceedings omits any reference to the burden of proof or the evidentiary standard.

E. Court oversight is not limited to mental health. The Court may engage in an unlimited inquiry about the youth's choices in finances, education, housing, and clothes (lines 58-65).

Fourth, the bill is manifestly unnecessary. There are extensive procedures in place for involuntary mental health commitments and guardianship proceedings. Adding overlapping Family Court proceedings in anticipation of expanding regressive outpatient treatment orders will complicate rather than improve the mental health system.

The Council may wish to share these observations with policymakers, including DSCY&F Administration, DHSS Administration, the Office of the Child Advocate, the ACLU, and the federal Court Monitor.

16. House Bill No. 317 (Employment Discrimination: Family Responsibilities)

This legislation was introduced on April 19, 2016. As of May 9, it had been released by the House Labor Committee and awaited action by the House.

The bill would add a protected class to Delaware's employment discrimination law - "family responsibilities". It would be defined as follows:

(9) “Family responsibilities” means the state of being, or the potential to become, a contributor to the support of a person or persons in a dependent relationship, irrespective of their number, including the state of being the subject of an order of withholding or similar proceedings for the purpose of paying child support or a debt related to child support.

The synopsis indicates that “five states and over 90 localities prohibit discrimination based on family responsibilities to some degree.”

The effect of the bill would ostensibly be broad.

There already exists a patchwork of laws which provide some protection against workplace discrimination involving prospective and current caregivers. Pregnant women are protected under both federal and State law [19 Del.C. 711(a)(1)]. Moreover, the Americans with Disabilities Act (ADA) prohibits discrimination because of the disability of an individual with whom the worker has a relationship or association, such as a child, spouse or parent. See 42 U.S.C. 12112(b)(4). The Equal Employment Opportunity Commission (EEOC) offers the following example: “(A)n employer could not refuse to hire a job applicant whose wife has a disability because the employer assumes that the applicant would have to use frequent leave and arrive late due to his responsibility to care for his wife.” See EEOC, “Enforcement Guidance: Unlawful Disparate Treatment of Workers with Caregiving Responsibilities” (2007), Section II. E. It is unclear if Delaware State law covers disability-based discrimination based on a worker’s association with a person with a disability. See 19 Del.C. §§720-728. House Bill No. 317 would cover any State law gap in this context. It would also cover caregivers assisting children without disabilities or the elderly who may not have quite reached the threshold of disability under ADA standards.

The sponsors may wish to consider improving the bill by explicitly adding provisions akin to the “reasonable accommodations” protections for pregnant workers and workers with disabilities. See 19 Del.C. §§710(18), 711(3)a, and 722(6). Reasonable accommodations for a caregiver could include modified work schedules and job restructuring.

The Council may wish to consider sharing a positive analysis of the bill consistent with these observations.

17. Senate Bill No. 230 (Supported Decision-making)

This legislation was introduced on April 14, 2016. It was released from the Senate Health & Social Services Committee on April 20. As of May 9, it awaited action by the Senate.

In recent years, the federal Administration on Aging and the Administration for Intellectual and Developmental Disabilities have promoted the availability of supported decision-making options. Their rationale is that both the elderly and individuals with disabilities may benefit from the availability of assistance which is respectful of their autonomy while offering a menu of supports from which they can choose.

Many national organizations are also promoting the availability of supported decision-making for persons with disabilities. For example, the national ARC and American Association on Intellectual and Developmental Disabilities (AIIDD) adopted a position statement in April, 2016, “Autonomy, Decision-Making Supports, and Guardianship”. The national position statement includes the following guidance:

- States should provide systemic access to decision-making supports for all individuals with IDD.
- Each individual...should receive the preparation, opportunities, and decision-making supports to develop as a decision-maker over the course of his or her lifetime. All persons with I/DD can participate in their own affairs with supports, assistance, and guidance from others, such as family and friends. People with I/DD should be aware of and have access to decision-making supports for their preferred alternatives.
- Less restrictive means of decision-making supports (e.g. health-care proxies, advance directives, supported decision-making, powers of attorney, notarized statements, representation agreements, etc.) should be tried and found to be ineffective in ensuring the individual’s decision-making capacity before use of guardianship as an option is considered.

Representatives of the Department of Health & Social Services, Office of the Public Guardian, Disabilities Law Program and multiple state councils formed a workgroup to prepare enabling legislation resulting in Senate Bill No. 230. The legislation does not supplant guardianship, powers of attorney, or other options available to help individuals with disability-related limitations. Rather, it is part of a continuum of tools and resources to facilitate decision-making.

In nutshell, the Department of Health & Social Services will publish a form which a “principal “can execute defining the scope of authorized assistance (lines 88-89 and 163). The “supporter” must also sign the form and agree to abide by its terms (lines 98-102). If authorized, the supporter assists the principal in understanding financial, healthcare, and other information (lines 113-114); obtaining information (lines 115-117); making appointments (lines 118-119); and helping organize and keep track of information (lines 120-121).

The bill includes many safeguards:

- A. The DHSS form must be used (lines 88-90).
- B. The form must be signed in the presence of two witnesses (line 91).
- C. The supporter and witnesses must not be disqualified based on potential conflicts of interest (lines 92-95 and 124-131).
- D. Supporters are barred from misusing their role or information (lines 132-137).
- E. Supporters must protect the confidentiality of information (lines 159-161).

F. The principal can revoke the form agreement at any time (lines 105-106).

The supporter essentially assists and facilitates decision-making and implementation of a principal's decisions. The supporter is not a substitute decision-maker (lines 12-13).

Since the legislation enhances the scope of assistance available to individuals, with safeguards, it may merit endorsement.

A **motion** was made and **approved** to accept the recommendations of the committee as submitted.

MEMBERSHIP

The committee had nothing to report.

PERSONNEL COMMITTEE

The committee had nothing to report.

AD HOC COMMITTEES

There were no ad hoc committee reports.

OUTSIDE COMMITTEE UPDATES

Dafne shared information regarding the development of a Disability History display. This is a multiyear project whose purpose is to display in some format, the history of disability rights in our state. Many states around the nation are developing or have developed something similar. The group met this week and is collecting items and information for the display.

Robert announced visitors for the evening and advised members that copies of all letters and responses are available for viewing at the back of the room.

A **motion** was made **to adjourn** the meeting. The **motion** was **approved**. The meeting was adjourned at 8:17 p.m.